



The Death of a Child

THE GRIEF OF THE PARENTS:
A LIFETIME JOURNEY



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The Death of a Child The Grief of the Parents: A Lifetime Journey

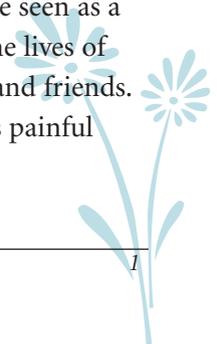
*The morning glory blooms but for an hour
and yet it differs not at heart
from the giant pine
that lives for a thousand years
— Teitoku Matsunaga, Japanese Poet*

There is no more devastating loss than the death of a child. Sudden death is a contradiction to everything that is known to be true in life. Losing a child to sudden death is a disruption in the natural law and order of life. It is a heartbreak like no other. Parental grief is different from other losses—it is intensified, exaggerated and lengthened.

“Children are not supposed to die...Parents expect to see their children grow and mature. Ultimately, parents expect to die and leave their children behind...This is the natural course of life events, the life cycle continuing as it should. The loss of a child is the loss of innocence, the death of the most vulnerable and dependent. The death of a child signifies the loss of the future, of hopes and dreams, of new strength, and of perfection” (Arnold and Gemma 1994, iv,9,39).

Grieving parents say that their grief is a lifelong process, a long and painful process... “a process in which [they] try to take and keep some meaning from the loss and life without the [child]” (Arnold and Gemma 1983, 57). After a child’s death, parents embark on a long, sad journey that can be very frightening and extremely lonely—a journey that never really ends. The hope and desire that healing will come eventually is an intense and persistent one for grieving parents.

The child who died is considered a gift to the parents and family, and they are forced to give up that gift. Yet, as parents, they also strive to let their child’s life, no matter how short, be seen as a gift to others. These parents seek to find ways to continue to love, honor, and value the lives of their children, and to make the child’s presence known and felt in the lives of family and friends. Bereaved parents often try to live their lives more fully and generously because of this painful experience.





The Process of Grief

Grief is a process. Although parents would wish otherwise, grief cannot be bypassed or hurried; it must be allowed to happen. Parents do not go through grief and come out the other side as before the loss. Grief changes parents.

One approach to understanding bereavement, developed by Dr. J.W. Worden (2002), identifies grief not as a succession of phases through which a person passes with little or no control, but as four tasks for the bereaved person:

Accepting the reality of the loss: When someone dies, there is always a sense that it hasn't happened. The first task of grieving is to come full face with the reality that the child is dead, that the child is gone and will not return. The opposite of accepting the loss is not believing through some type of denial. Denial usually involves either the facts of the loss, the significance of the loss to the survivor, or the irreversibility of the loss. To accomplish this task, the parent must talk about the dead child and funeral, as well as the circumstances around the death.

Working through the pain of grief: It is necessary to acknowledge and work through the pain of grief or it will manifest itself through some symptoms or atypical behavior. Not everyone experiences the same intensity of pain or feels it in the same way, but it is impossible to lose someone with whom you have been deeply attached without experiencing some level of pain. The negation of this second task is not to feel.

People may avoid feeling pain by using thought stopping procedures or by avoiding reminders of the child. Many emotions such as shock, anger, guilt and depression may be expressed. The bereaved need to allow themselves to indulge in the pain: to feel it and know that one day it will pass. Some say it is easier to express emotions with someone who knew the child or who can relate to the experience directly.

Adjusting to an environment in which the deceased is missing: Caring for a child takes an amazing amount of time and energy. Parents and other caregivers once consumed with the constant task of meeting the needs of a child are suddenly forced into inactivity. Where responsibility was, is now emptiness. During this adaptation to loss, people can work to avoid promoting their own helplessness by gradually reforming schedules and responsibilities. Creating meaningful rituals like a special memorial or keeping a journal or writing poetry are helpful components of completing this task.



Emotionally relocating the deceased and moving on with life: Survivors sometimes think that if they withdraw their emotional attachment, they are somehow dishonoring the memory of the child. In some cases, parents are frightened by the prospect of having another baby because he or she might also die. For many people, this task is the most difficult one to accomplish. They may get stuck at this point and later realize that their life in some way stopped at the point the loss occurred.

Some bereavement experts note the grieving process includes not only the parent adapting to the loss and returning to functioning in their life, but also includes changing and maintaining their relationship with the infant or child. It is normal for parents to report that they having an on-going relationship with their child through their memories and mental life.

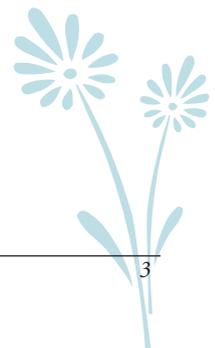
(Worden J.W. 2002)

Factors that may interfere with the grief process:

- Avoiding emotions
- Overactivity leading to exhaustion
- Use of alcohol or other drugs
- Unrealistic promises made to the deceased
- Unresolved grief from a previous loss
- Judgmental relationships
- Resentment of those who try to help

Complicated grief is delayed or incomplete adaptation to loss. In complicated grief, there is a failure to return, over time, to pre-loss levels of functioning, or to the previous state of emotional well-being. Grief may be more difficult in younger parents, women, and persons with limited social support, thus increasing their risk for complicated grief. The grief surrounding a child's death is unique in its challenges and may necessitate professional counseling from the clergy, grief counselor, family physician, or mental health professional.

(Burnett L.B. 2004)





Sudden Infant Death

The impact of Sudden Infant Death Syndrome (SIDS) presents unique grieving factors and raises painful psychological issues for the parents and family as well as those who love, care for, and counsel them. SIDS parents must deal with a baby's death that is unexpected and unexplained, a death that cannot be predicted or prevented, an infant death so sudden that it leaves no time for preparation or goodbyes, and no period of anticipatory grief. In many cases, parents of SIDS babies are very young and are confronted with grief for the first time.

SIDS often occurs at home, forcing parents and sometimes siblings or other children to witness a terrible tragedy and possibly scenes of intense confusion. In some cases, the parents themselves are the ones who find the child dead and they must always live with that memory. In other cases, the parents may feel overwhelming guilt or anger if the death occurred while the child was in child care. They may feel that the baby might not have died if they had been caring for the infant. SIDS parents also are very often plagued by "if only's" that they are never able to resolve. They mentally replay such thoughts as: "If only I hadn't put the child down for a nap when I did." "If only I had checked on the baby sooner." "If only I had not returned to work so soon." "If only I had taken the baby to the doctor with that slight cold." Professionals need to provide parents with reliable information, as well as emotional support in these situations.

SIDS parents, relatives, child care providers, health care professionals, and other adults feel helpless in trying to explain the unexplainable to other young children who may have been present at the time of the baby's death. It is especially difficult for children to understand why a baby died when the infant didn't appear to be sick. Also, in some cases parents are required to explain SIDS to adults who are misinformed or know nothing about the syndrome.

In most SIDS deaths, the autopsy findings may help answer questions. Parents are often anxious to consult with the pathologist after the autopsy. Discussing the autopsy results often helps most parents accept the reality of their infant's death. The pathologist reviews the autopsy results, explaining in terms the parents can understand how these findings point to a determination of cause of death. The pathologist should also take the time to answer parents' questions (Valdes-Dapena, 1995).

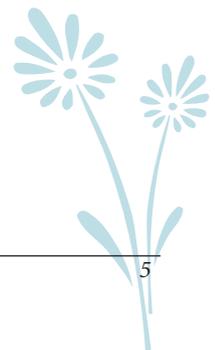
Friends and family members should try to do all they can to show their concern and help the parents in keeping memories of their baby alive. For most SIDS parents, it is also reassuring for



others to try to mention special things they noticed about the baby and to remember the child's birthday or the anniversary of the death. By extending these personal and sensitive gestures, loving and concerned relatives, friends, and caregivers can become a source of reassurance and comfort for the grieving parents.

Some SIDS babies are so young when they die that family members and friends never had a chance to welcome them. They may have missed sharing the parents' excitement over the birth and affirming the child's existence. Many individuals do not understand the depth of parental attachment to a very young child. Bereaved SIDS parents should not be made to feel that others don't want to hear them, that others won't permit them to openly grieve. The parents of SIDS babies want their child's short life to matter not only to them, but to their families and friends, to the others in their "circle of concern," and to the world.

"All too frequently, a SIDS loss is not socially validated in the same way other deaths are. Others often fail to recognize that, despite the brevity of the child's life, the family's attachment to that child is strong and deep and has been present in various ways since the knowledge of conception" (Rando 1986,167).





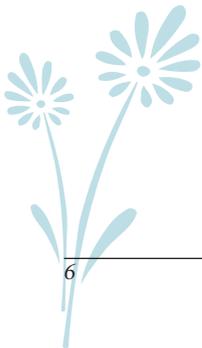
Fathers and Grief

“**W**hen is it my turn to cry? I’m not sure society or my upbringing will allow me a time to really cry, unafraid of the reaction and repercussion that might follow. I must be strong, I must support my wife, because I am a man. I must be the cornerstone of our family because society says so, my family says so, and, until I can reverse my learned nature, I say so” (A father in DeFrain, J., L. Ernst, D. Jakub, and J. Taylor, J. 1991, 112).

Although both mothers and fathers grieve deeply when such a tragedy occurs, they grieve differently. Fathers are expected to be strong for their partners, to be the “rock” in the family. All too often fathers are considered to be the ones who should attend to the practical but not the emotional aspects surrounding the death; they are expected to be the ones who should not let emotions show or tears fall outwardly, the ones who will not and should not fall apart. Men are often asked how their wives are doing, but not asked how they are doing.

Such expectations place an unmanageable burden on men and deprive them of their rightful and urgent need to grieve. This need will surface eventually if it is not expressed. It is not unusual for grieving fathers to feel overwhelmed, ignored, isolated, and abandoned, but many say that such strong emotions are very difficult to contain after their child’s death.

A father’s grief needs to be verbalized and understood by his partner, other family members, professionals, coworkers and friends, and by anyone who will listen. Fathers repeatedly say that for their own peace of mind, they (and those who care about them) need to move away from this mind set and allow themselves to grieve as they need to.





Families Needing Additional Support

The tragedy of a child's death brings profound pain to all affected, and it presents incredibly difficult and unusual problems for all grieving parents. For some parents, the effects of such a complicated and devastating tragedy can be further compounded when the death occurs in a family already experiencing added stress in their lives, such as substance abuse or domestic violence. There are some parents for whom there is no "circle of concern" or extended family. There are also families who choose not to seek out a support network for their own reasons.

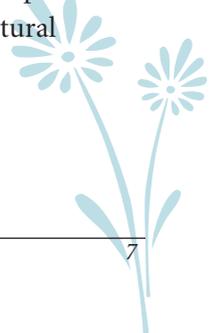
It is important to assess each family's special needs and preferences. Additional resources for families include hospice organizations, local health departments, bereavement support programs, and community or religious leaders or healers. Each family's cultural beliefs and practices must be honored during the bereavement process.

Non-Traditional Families

When a non-traditional family experiences the death of an infant, the community's response may be less supportive to that family. It may be necessary to assist the family to seek out support networks that will best address their needs. Examples of a non-traditional family include:

- Single parent
- Unmarried parents
- Teenage parents
- Step-parents
- Parents in blended families
- Adoptive and foster parents
- Gay and lesbian parents

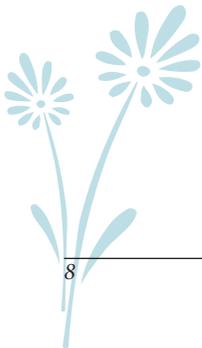
All of these parents and those in traditional families may find their grief unusually complicated. Regardless of the family's composition, parental experience, coping strategies, and cultural practices are unique for each family.





Ways to Comfort a Grieving Parent

- Acknowledge the child's death by telling the parent(s) of your sadness for them and by expressing love and support and trying to provide comfort.
- Allow the parent(s) to express feelings without imposing your views or feelings about what is appropriate behavior. Avoid telling the parent(s) you know just how they feel.
- Allow the parent(s) to cry—it is appropriate to cry with them.
- Visit and talk with the family about the child who died; ask to see pictures or memories the family may have. Refer to the child by name.
- Extend gestures of concern such as bringing flowers or writing a personal note expressing your feelings, letting the parent(s) know of your sadness for them.
- Attend the child's funeral or memorial service.
- Offer to go with the parent(s) to the cemetery in the days and weeks after the funeral, or find other special ways to extend personal or sensitive gestures of concern.
- Remember anniversaries and special days.
- Donate to a specific memorial in honor of the child.
- Make practical and specific suggestions, such as offering to stop by at a convenient time, bringing a meal, purchasing a comforting book, offering to take the other children for a special outing, or treating the parent(s) to something special.
- Respect the dynamics of each person's grief. The often visible expressions of pain and confusion shown by the grieving parent(s) are normal. Grief is an ongoing and demanding process.
- Keep in mind that the parent(s) may not be able to ask for help or tell you what they need.





From One Bereaved Parent to Another

When are you ready to live again? There is no list of events or anniversaries to check off. In fact, you are likely to begin living again before you realize you are doing it. You may catch yourself laughing. You may pick up a book for recreational reading again. You may start playing lighter, happier music. When you do make these steps toward living again, you are likely to feel guilty at first. “What right have I, you may ask yourself, to be happy when my child is dead?” And yet something inside feels as though you are being nudged in this positive direction. You may even have the sense that this nudge is from your child, or at least a feeling that your child approves of it (Horchler and Morris, 2003, 178).

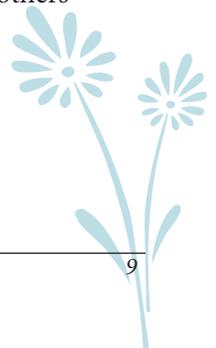
All newly bereaved parents must find ways to get through, not over, their grief—to go on with their lives. Each is forced to continue life’s journey in an individual manner.

Many bereaved parents find solace in their religion. Seeking spiritual comfort in a time of grief does not mean repressing the grief.

Many grieving parents also find comfort in rituals. Funerals or memorial services have served many parents as beautiful and meaningful ways of saying goodbye, providing a sense of closure after the child’s death. For others, sending announcement cards about the baby’s death, writing poems, keeping journals or writing down personal reflections or prayers, or volunteering with a parental bereavement group become ways to remember and honor the child who died.

Grief is the natural response to any loss. Healing for bereaved parents can begin to occur by acknowledging and sharing their grief.

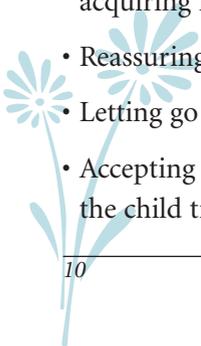
Friends and caregivers who care should grieve and mourn with the parents; and be willing to listen. Bereaved parents need to know that their child will be remembered, not just by them but also by family and friends. They need to have the child acknowledged and referred to by name. They want that child’s life to matter. They do not want to forget and they don’t want others to forget.





Ways That Help Parents Cope and Heal from the Sudden Loss of a Child

- Admitting to themselves and others that their grief is overwhelming, unpredictable, painful, draining, and exhausting—that their grief should not be diminished or ignored.
- Allowing themselves to be angry and acknowledging that they are vulnerable, helpless, and feeling disoriented.
- Trying to understand that to grieve is to heal and that integrating grief into their lives is a necessity.
- Acknowledging the need and desire to talk about the child who died as well as the moments and events that will be missed and never experienced with the child.
- Maintaining a belief in the significance of their child's life, no matter how short.
- Creating memorial services and other rituals as ways to commemorate the child's life.
- Deriving support from religious beliefs, a sense of spirituality, or a personal faith.
- Expressing feelings in journals, poetry, prayers, or other reflective writings or in art, music, or other creative activities.
- Trying to be patient and forgiving with themselves and others and refraining from making hasty decisions.
- Counting on, confiding in, and trusting those who care, listen, and hear, those who will walk with them, and not be critical of them, those who will try to understand their emotional and physical limitations, while also trying to understand and respect the limitations of their caretakers.
- Increasing their physical activity and maintaining a healthful diet.
- Volunteering their services to organizations concerned with support for bereaved parents.
- Obtaining help from traditional support systems, such as family, friends, professionals or religious groups, undergoing professional counseling, joining a parent support group, or acquiring information on the type of death that occurred as well as about their own grief.
- Reassuring themselves and others that they were and still are loving parents.
- Letting go of fear and guilt when the time seems right and the grief seems less.
- Accepting that they are allowed to feel pleasure and continue their lives, knowing their love for the child transcends death.





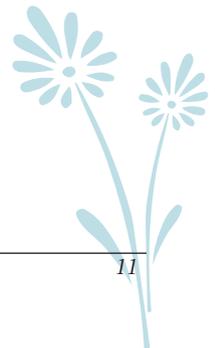
Conclusion

What has happened to these parents has changed their lives; they will never see life the same way; they will never be the same people. As they attempt to move forward, bereaved parents realize they are survivors and have been strong enough to endure what is probably life's harshest blow. By addressing their grief and coping with it, they struggle to continue this journey while making this devastating loss part of their own personal history, a part of their life's story, a part of their very being.

Eventually, time will cease to stand still for parents. Painful and terrible moments will still occur—striking, poignant, but in some ways comforting reminders of the child who died. There will also be regrets for experiences that were never shared. But at some unknown and even unexpected point, parents will come to realize that there can be good moments, even happy and beautiful moments, and it will not seem impossible or wrong to smile or laugh, but it will seem right and beautiful and a fitting way to honor and remember the child who died. One day, bereaved parents may come to be “surprised by joy” (Moffat 1992, xxvii).

“But in time...nature takes care of it; the waves of pain lose intensity a little and come less frequently. Then friends and relatives say the parents are getting over it, and that time heals all wounds. The parents themselves say that as the pain lessens, they begin to have energy for people and things outside themselves...This is a decision parents say [they] must make to live as well as they can in [their] new world...They can come to be happy, but never as happy.” Their perspective on this and everything has changed. Their child's death is the reason for this and is “a measure of the depth and breadth of the bond between parent and child” (Finkbeiner 1996,12, 20, 22, 23).

*Like a bird
Singing in the rain,
Let grateful memories
Survive in time of sorrow.
— Robert Louis Stevenson*





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Recommended Resources

Ash L.

Life Touches Life: A Mother's Story of Stillbirth and Healing

Troutdale, OR: New Sage Press, Inc., 2004. 192 p.

Available from New Sage Press Ltd., P.O. Box 607, Troutdale, OR 97060.

(503) 695-2211, (877) 695-2211 (toll-free), (503) 695-5406 (fax), info@newsagepress.com (e-mail),
www.newsagepress.com (Web site).

ISBN 0-93916-550-3.

Covington SN.

Silent Birth. When Your Baby Dies. Revised Edition

Minneapolis, MN: Fairview Press, 2003. 16 p.

Available from Fairview Press, 2450 Riverside Avenue, Minneapolis, MN 55454.

(800) 544-8207 (toll-free), (612) 672-4180, (612) 672-4980 (fax), press@fairview.org (e-mail),
www.fairview.org (Web site).

ISBN 57749-144-0.

First Candle/SIDS Alliance

Sudden Infant Death Syndrome: Surviving the Death of a Baby

Baltimore, MD: First Candle/SIDS Alliance, 2000. 11 p.

Available from National SIDS/ID Program Support Center (NSIDPSC)

1314 Bedford Avenue, Suite 210, Baltimore, MD 21208. (410) 415-6628, (800) 638-7437 (toll-free),
(410) 415-5093 (fax), kathleen.graham@firstcandle.org (e-mail),
www.firstcandle.org/health/health_human.html (Web site). Available in Spanish.

Hoppenbrouwers T, Hodgman J.

SIDS

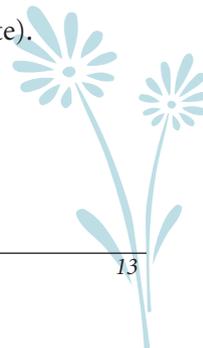
Los Angeles, CA: Women's and Children's Hospital, 2003. 93 p.

Available from Women's and Children's Hospital, Newborn Division Rm L919,

Attention Dr. T. Toke Hoppenbrouwers, 1240 Mission Road, Los Angeles, CA 90033.

toke@hoppenbrouwers.net (e-mail), www.hoppenbrouwers.net/toke/sids.asp (Web site).

ISBN 0-9742663-0-2.



Horchler JN, Rice R.

SIDS and Infant Death Survival Guide: Information and Comfort for Grieving Family and Friends and Professionals Who Seek to Help Them

Cheverly, MD: SIDS Educational Services, 2003. 320 p.

Available from SIDS Educational Services, Inc., 2905 64th Avenue, Cheverly, MD 20785. (301) 322-2620, (877) 935-6839 (toll-free), (301) 322-9822 (fax), sidses@aol.com (e-mail), www.sidssurvivalguide.org (Web site). Available in Spanish. ISBN 0-9641218-2-4.

Johnson J, Johnson SM.

Children Die, Too: A Book for Parents Who Have Experienced the Death of a Child

Revised Edition

Omaha, NE: Centering Corporation, 2004. 10 p.

Available from Centering Corporation, P.O. Box 4600, Omaha, NE 68104. (402) 553-1200, (402) 553-0507 (fax), centering@centering.org (e-mail), www.centering.org (Web site). Available in Spanish. ISBN-1-56123-029-4.

Johnson J, Johnson SM, et al.

Miscarriage: A Book for Parents

Omaha, NE: Centering Corporation, 2004. 24 p.

Available from Centering Corporation, P.O. Box 4600, Omaha, NE 68104. (402) 553-1200, (402) 553-0507 (fax), centering@centering.org (e-mail), www.centering.org (Web site). Available in Spanish. ISBN 56123-007-3.

Limbo RK, Wheeler SR.

When a Baby Dies: A Handbook for Healing and Helping

La Crosse, WI: Bereavement Services, 2003. 165 p.

Available from Bereavement Services, 1910 South Avenue, La Crosse, WI 54601. (800) 362-9567 (toll-free), (608) 775-4747, (608) 775-5137 (fax), berservs@gundluth.org (e-mail), www.bereavementprograms.com (Web site). ISBN 0-9607098-4-3.

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Bereavement Counseling for Sudden Infant Death Syndrome and Infant Mortality: Core Competencies for the Health Professional

McLean, VA: Association of SIDS and Infant Mortality Programs, 2004. 39 p.

Available from the Association of SIDS and Infant Mortality Programs, 8280 Greensboro Drive, Suite 300, McLean, VA. 2004. (800) 930-7437 (toll-free), (703) 902-1230 (fax), info@sidsprojectimpact.com (e-mail), www/asip1.org (Web site).



Nelson T.

A Guide for Fathers: When a Baby Dies

St. Paul, MN: A Place to Remember, 2004. 66 p.

Available from A Place to Remember, 1885 University Avenue, Suite 110, St. Paul, MN 55104. (612) 645-7045, (800) 631-0973 (toll-free), (612) 645-4780 (fax), aptr@aplacetoremember.com (e-mail), www.aplacetoremember.com (Web site). ISBN-0-96508-484-1.

Peterson J.

Heart Works: A Father's Grief

Portland, OR: Heart Works Publishing, 2003. 83 p.

Available from Heart Works Publishing, 930 SE Sandy Boulevard, Portland, OR 97214. (503) 236-1350, (503) 236-8555 (fax), jerre@negativeperfection.com (e-mail), www.heart-works-publishing.com (Web site). ISBN 0-9729377-1-4.

Reed ML.

Grandparents Cry Twice: Help for Bereaved Grandparents

Amityville, NY: Baywood Publishing Company, Inc., 2000. 127 p.

Available from Baywood Publishing Company, Inc. 26 Austin Avenue, P.O. Box 337, Amityville, NY 11701. (800) 638-7819 (toll-free), (631) 691-1270, (631) 691-1770 (fax), info@baywood.com (e-mail), www.baywood.com (Web site). ISBN 0-89503-204-X.

Sanders DB.

When Your Baby Dies...A Gentle Guide for Teenage Parents

Rancho Cordova, CA: California SIDS Program, Maternal and Child Health Branch, California Department of Health Services, 2003. 18 p.

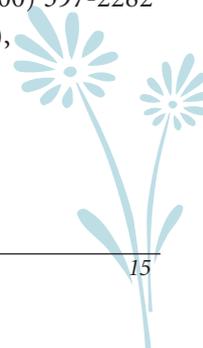
Available from California SIDS Program, 3164 Gold Camp Drive, Suite 220, Rancho Cordova, CA 95670-6052. (916) 266-7437, (800) 369-7437 (toll-free in CA), (916) 266-7439 (fax), info@californiasids.com (e-mail), www.californiasids.com (Web site).

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The Death of a Child: Reflections for Grieving Parents

Chicago, IL: ACTA Publications, 2004. 160 p.

Available from ACTA Publications, 4848 N. Clark Street, Chicago, IL 60640-4711. (800) 397-2282 (toll-free), (773) 271-1030, (800) 397-0079 (fax), actapublications@aol.com (e-mail), www.actapublications.com (Web site). ISBN 0-87946-260-4.



The Compassionate Friends

Stillbirth, Miscarriage and Infant Death-Understanding Grief

Oak Brook, IL: The Compassionate Friends, 2003. 2 p.

Available from The Compassionate Friends, P.O. Box 3696, Oak Brook, IL 60522-3696. (877) 969-0010 (toll-free), (630) 990-0246, nationaloffice@compassionatefriends.org (e-mail), www.compassionatefriends.org (Web site). Available in Spanish.

The Compassionate Friends

When a Child Dies...The Compassionate Friends Can Help

Oak Brook, IL: The Compassionate Friends, 2004. 2 p.

Available from The Compassionate Friends, P.O. Box 3696, Oak Brook, IL 60522-3696. (877) 969-0010 (toll-free), (630) 990-0246, nationaloffice@compassionatefriends.org (e-mail), www.compassionatefriends.org (Web site). Available in Spanish.

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Selected Resources for Grieving Parents, their Families, Friends, and Other Caregivers

National SIDS/Infant Death Resource Center, Revised 2005. 48 p.

Available from the National SIDS/Infant Death Resource Center, 8280 Greensboro Drive, Suite 300, McLean, VA. 22102. (866) 866-7437 (toll-free), (703) 821-8955, (703) 821-2098 (fax), sids@circlesolutions.com (e-mail), www.sidscenter.org (Web site).

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A Child's View of Grief: A Guide for Parents, Teachers, and Counselors

Ft. Collins, CO: Companion Press, 2004. 54 p.

Available from Companion Press, an imprint of the Center for Loss and Life Transition, 3735 Broken Bow Road, Fort Collins, CO. 80526. (970) 226-6050, www.centerforloss.com (Web site). ISBN-1-879651-43-2.

U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau

After Sudden Infant Death: Facing Anniversaries, Holidays, and Special Events

National SIDS/Infant Death Resource Center, Revised 2005. 16 p.

Available from the National SIDS/Infant Death Resource Center, 8280 Greensboro Drive, Suite 300, McLean, VA. 22102. (866) 866-7437 (toll-free), (703) 821-8955, (703) 821-2098 (fax), sids@circlesolutions.com (e-mail), www.sidscenter.org (Web site).

